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ABSTRACT

This paper discusses public education and the individual's rights to a quality education in relation to legal and civil responsibility. The proposed policy entitled "Protection of Human Subjects," issued by the United States Department of Health, Education, and Welfare (DHEW), is discussed in terms of educational research. The policy guidelines suggest that no projects involving risk for human subjects will be funded by DHEW unless the applicant (investigator) has established a peer review team, the results of which must be received by DHEW for further evaluation by the Secretary. It is argued that educational researchers, as part of the larger body of behavioral scientists, must take immediate steps to confront the issues involving the use of human subjects. There must be a concerted effort to establish free-flowing lines of communication, not only within the educational research community, but throughout the public sector as well. The educational research community must develop a code of ethics which protects the rights and dignity of the human subject while fostering the conduct of meaningful, productive research. (TS)

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THE READING PROBLEM:
A TIME FOR DUAL ACCOUNTABILITY THE SCHOOL BOARD AND THE COMMUNITY

Allen A. Mori, Ph.D.
Paper Read Before the International
Reading Association Convention
Anaheim, Califfornia
May 10, 1976

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In 1973, William F. Pierce, who at the time was the newly appointed U.S. Deputy Commission for Occupational and Adult Education said:

"The current catchword in public administration at all levels is accountability. Although the techniques for responding to the concept of accountability are many and varied, the financial problems currently faced by the educational system make it obvious that local administrators and program managers will ultimately be forced to decide the fate of a program from the standpoint of the most efficient use of scarce resources."

It has become increasingly evident that public education, the nation's largest consumer industry, is about to be entwined in a maelstrom of consumer-oriented litigation involving the individual's right to a quality education.

In 1972, Saretsky and Mecklenburger, cautioned us to prepare for court actions by interest groups seeking redress for inappropriate educational practices.

Clearly, the parallels have been established. Physicians and attorneys who perform negligently may be sued for malpractice. When a consumer product fails to function properly, the product producer may be held liable. Thus, to what extent can the schools and the school board be held accountable for the selection of inappropriate instructional materials, strategies, etc.

One may suggest the answer to this question may soon be provided.

Addressing this issue, Susanne Martinez, attorney for the plaintiff in the now famous Peter Doe case, said:

"The Peter Doe case is simply a forerunner of an effort on the part of parents to bring to focus, through the judicial system, attention upon the fact that the schools, the educational systems of this society, have failed to provide the Peter Does of this country the kind of education to which they're entitled."

The Peter Doe case (Peter Doe v. San Francisco Unified School District) involves a complaint originally filed in the Superior Court of California against the San Francisco Unified School District, its Board of Education.



and Superintendent of Schools; the State Department of Education, its
Board of Education; the State Superintendent of Public Instruction; and
100 defendants alleged to be the agents or employees of public agencies.

A brief summary of the facts and legal intentions in this case may prove helpful. The plaintiff was an 18-year-old white male high school graduate. Personnel from the San Francisco school district had certified that Doe had normal intelligence. During the course of his thirteen year educational experience, he maintained average grades, was not involved in any serious disciplinary problems, and maintained regular school attendance. He advanced on schedule through the school system and was awarded a regular high school diploma. Throughout his educational experience, Doe's parents voiced concern over his apparent reading difficulties, but were assured by school officials that Peter was reading at the average level and had no special problems.

After graduation, Peter's parents arranged for him to be examined by two private reading specialists. Both indicated that he was reading at the fifth-grade level. Since the administration of the tests, Peter had received private tutoring and made progress in improving his reading level approximately two grades in eight months.

The lawyers for the plaintiff claimed that the school district's liability can be cited on nine distinct legal grounds. Only those relevant to this presentation will be discussed:



The source of this summary is the Youth Law Center, San Francisco, California. The summary appeared in Saretsky, G. The Strangely Significant Case of Peter Doe, Phi Delta Kappan, 54, 1973, 589-592.

- General Negligence; in that the schools negligently failed to provide Doe with adequate instruction, guidance, counseling, and/or supervision in basic academic skills;
- 2. Misrepresentation: in that the schools falsely represented to

 Doe's parents that he was performing at or near grade level

 and was not in need of special instruction when, in fact, the

 plaintiff was drastically below grade level; and
- 3. Breach of Statutory Duty: in that the schools violated relevant provisions of the California Education Code requiring the school districts to design a course of instruction to meet the needs of individual students.

In addition, the complaint contended that as a result of the defendant's actions, the plaintiff:

- suffered a loss of earning capacity;
- was unqualified for employment except in the most menial jobs requiring little or no reading ability;
- 3. had suffered mental distress; and
- 4. that the injuries would result in total damage in the sum of \$1,000,000 and the costs of private reading tutoring and court costs. The major defense action selected by the defendants was the filing of a demurrer. The demurrer contended that even if all the facts were true, they did not constitute grounds to rule in favor of the plaintiffs.

As of this date, the California Superior Court sustained the school district's demurrer and dismissed the Doe complaint. However, an appeal has been filed with the Appellate Court, and a decision has yet to be rendered.

. As interested citizens, and more specifically, as trained professional,

educators, the ramifications of a victory for the plaintiff in Appellate Court would be substantial. For instance, if the Appellate Court rules in favor of Doe based upon his attorney's claim of negligence, then students who suffer educational harm could sue the schools for damages resulting from educational malpractice (Abel, 1974).

Exactly what are the implications of this decision? In a positive sense, school districts and professional educators may be encouraged to search for more effective and efficient methods for helping students to attain a minimal level of proficiency. Furthermore, it might lead to a greater sensitivity among educators for the implications of their acts.

On the other hand, one may examine the medical profession's reaction to the escalation of malpractice suits for a possible parallel. In many cases, physicians are ordering costly series of diagnostic tests to substantaite their diagnoses. Thus this extreme caution may have an inhibiting effect on medical practice. Perhaps the parallel effect may occur in education. School boards, administrators, and teaching personnel may establish rigid guidelines which would have the effect of stifling educational innovation and creativity.

Dr. Cleland has asked me to address some remarks to a parallel situation involving the use of human subjects for research endeavors in education. As educators interested in furthering educational research in reading and in promoting the translation of research findings into practice, we all may soon be faced with a legal and moral dilemma involving accountability and the rights of human subjects.

THE MORAL AND LEGAL DIMENSIONS IN PROTECTING HUMAN RIGHTS IN EDUCATIONAL RESEARCH

Recent events in the political and social milieu in the United States have brought about increased public awareness and sensitivity to the issues

involving the privacy and dignity of the individual citizen. Concomitantly, public agencies, particularly schools and universities, have bowed to public pressure and legislation and are allowing students and parents to examine once-confidential school folders and records. The profound impact of these politico-socio-moral issues upon research in public education remains to be seen. However, one can assume that the reluctance of school officials to accept outside researchers probing into the various functions of the school district will be greatly heightened by the accountability, privacy, and right to access issues. The consequences for the conduct of meaningful educational research in schools could be alarming.

Societal concern for the appropriateness of using humans as subjects for research did not always exist. In fact, until most recently, it was common practice to use human subjects for research endeavors with little concern for the legal, ethical, and moral implications of this practice. During the early 1900s it was much easier to obtain a human subject than it was to experiment on animals.

Early rulers in Europe routinely assigned members of the lower classes, the mentally and physically infirm, and prisoners to researchers for use in carious projects. It became common practice to rationalize the use of human subjects, particularly second and third class citizens, in research projects to benefit the common good of all mankind. Eventually, such rationalizations became firmly rooted in the traditions of societies that commonly espoused the principle that the "ends justified the means". The disregard for the rights of man and the dignity of the human being reached a low point with the disclosures of the heinous practices of Nazi scientists in the 1940s. The use of human subjects for research purposes and the accompanying atrocities perpetrated against these individuals are now well-documented evidence of the

most infamous period of research abuses in the recorded history of mankind.

The Nuremberg trials and the resultant Nuremberg Code enlightened a largely apathetic public to the need for protecting the human research subject. Although the disclosures of this period served to heighten interest, professional attention to the development of widely accepted modes of conducting research with human subjects, has not been seriously maintained for more than 15 years.

Research endeavors have generated public concern in recent years.

Articles which appeared in the newspapers in February of 1975, described a project financed by the Department of Health, Education, and Welfare in which the "spines of 32 healthy, premature babies were tapped at New York Hospital-Cornell Medical Center between 1956 and 1962 without their parents knowledge or consent". Disclosures in 1972 of the Tuskegee study in which United States Public Health Service physicians observed for some 30 years the effects of untreated syphilis on black men in rural Alabama outraged many individuals and contributed to the growing concern over experimentation with human subjects.

At a National Academy of Sciences Forum held in Washington, D.C., in February of 1975 (New York Times, February 22, 1975) some 500 physicians, lawyers, ethicists, researchers, philosophers, and other concerned citizens debated and discussed the perplexing problems of human experimentation.

According to the author of this article, it was the largest meeting ever held on the ethics of human experimentation. Complex issues involving the integrity of the individual's right versus society's gain, informed consent, and coercion of subjects were presented. The distinguished forum was unable to resolve these issues, not did they know the extent of current human experimentation, that is precise numbers and ages of individuals serving as subjects for research projects in hospitals, medical facilities, schools and prisons. Many

forum participants acknowledged the need for continued research efforts to combat the crippling diseases besetting mankind, but warned against continued abuses resulting from unethical practices and improper design of research projects. While regulations have been adopted for federally funded research projects, most forum participants indicated that these regulations were inadequate. Casper W. Weinberger, then Secretary of the Department of Health, Education and Welfare, noted that unclear ethical guidelines are presenting a dilemma. Until clear principles are formulated governing the conduct of research with human subjects and definitions are established for informed consent, meaningful scientific experimentation could come to a halt.

The problem of the protection of human subjects, social institutions, and researchers continues to be a concern for the members of the research community.

According to Visscher (1969, p.323), one of the earliest references to safeguarding human subjects in research endeavors appeared in Thomas Percival's Medical Ethics first published in 1803. Percival outlined 31 rules "Of Ethical Conduct, Relative to Hospitals or Other Medical Charities". Rule Twelve provides some interesting insights, and evidence that Percival's concerns predated and perhaps served as a basis for later efforts to codify ethical principles. This rule stated:

Whenever cases occur, attended with circumstances not heretofore observed, or in which the ordinary modes of practice have been attempted without success, it is for the public good, and in an especial degree advantageous to the poor...that new remedies and new methods of chirurgical treatment should be devised. But in the accomplishment of this salutary purpose, the gentlemen of the faculty should be scrupulously and conscientiously governed by sound reason, just analogy, or well authenticated facts. And no such trials should be instituted without a previous consultation of the physicians or surgeons according to the nature of the case...

Percival's treatise contains the foundation of later documents
especially those areas which Percival called "sound reason, just analogy,
and well authenticated facts". The concluding statement of Rule Twelve
alludes to peer review, a process which has become a hallmark of later
documents proposing guidelines for research with human subjects.

According to Lowe (1969), the first large scale attempt to provide protection for the basic rights of human subjects in a variety of experimental settings occurred as a result of the Nuremberg Trials. The Nuremberg Code set forth ten principles which were to serve as guidelines for the conduct of medical research with human subjects.

The principles of the Nuremberg Code, while broad and open to varying interpretations, did establish a doctrine of ethical procedures for the conduct of research with human subjects. The now familiar concepts of informed consent, the good of society, avoidance of undue physical or mental suffering, degree of risk, protection of the subject, and uncoerced right to terminate a project highlighted in the Nuremberg Code served as guidelines for later attempts at establishing codes of ethics.

In 1964 the World Medical Assembly drafted and adopted the Declaration of Helsinki. According to Lowe (1969), this document was more complex and comprehensive than the Nuremberg Code because it recognized the significant difference in experiments in which pharmocological agents have a potential therapeutic effect and those in which there is no very apparent benefit, and it also recognized instances where informed consent is not possible. Essentially the Declaration of Helsinki covers the same broad areas as the Nuremberg Code, yet does little to precisely identify and define important sources of ethical misconduct. The essential problem with the Nuremberg Code and the Declaration of Helsinki is that of purposeful vagueness.

By stating ethical guidelines in the broadest possible terms, the researcher is given a free hand to interpret the principles according to his preconceived notion of the significance of the experimentation.

Golann (1969) described the attempt of the American Psychological Association's (APA) Committee on Scientific and Professional Ethics to develop a formal code of ethics as early as 1947. In 1953 the formal APA code of ethics was adopted. However, continued changes in the society's concern with the entire human experimentation problem caused the Board of Directors of the APA to appoint an Ad Hoc Committee on Ethical Standards for Psychological Research subjects. The result of the work of this Ad Hoc committee was a document entitled Ethical Principles in the Conduct of Research with Human Participants. The APA guidelines were an effort to prevent abuses in the conduct of human experimentation by providing more precise ethical principles. As one might expect, reactions by APA membership to these guidelines have been mixed. Some psychologists indicated that the guidelines were too precise and served too restrict meaningful research, others claimed they were so broad that they permitted research behavior deemed unethical.

In 1966, the House of Delegates of the American Medical Association (AMA) adopted Ethical Guidelines for Clinical Investigation. This code recognizes the need for the physician to obtain voluntary consent from the patient or a legally authorized representative in cases where the patient is unable to consent.

The vagueness of the AMA code allows each individual researcher to make the critical decisions involving the preservation of the dignity and rights of the human subject. While the safeguard of informed consent is detailed in the AMA code, it has not been painstakingly and precisely delineated to prevent potential subjects from consenting without fully comprehending the nature of study.

In an effort to protect human subjects in projects funded by the federal government, the United States Department of Health, Education, and Welfare (HEW) has issued a proposed policy entitled Protection of Human Subjects. The proposed guidelines suggest that no projects involving risk for human subjects will be funded by HEW unless the applicant (investigator) has established a peer review team, the results of which must be received by HEW for further evaluation by the Secretary.

Four aspects of the HEW's proposed guidelines warrant some brief discussion. The first aspect, informed consent is present in all policy guidelines and is defined by HEW as (Federal Register, 39, 105, Thursday, May 30, 1974, p. 18917):

knowing consent of an individual or his legally authorized representative, so situated as to be able to exercise free power of choice without undue inducement or any element of force, fraud, deceit, duress, or other form of constraint or coercion. The basic elements of information necessary to such consent include:

- A fair explanation of the procedures to be followed, and their purposes, including identification of any procedures which are experimental;
- A description of any attendant discomforts and risks reasonably to be expected.
- 3. A description of any benefits reasonably to be expected;
- 4. A disclosure of any appropriate alternative procedures that might be advantageous for the subject;
- 5. An offer to answer any inquiries concerning the procedures; and
- 6. An instruction that the person is free to withdraw his consent and to discontinue participation in the project of activity at any stime without prejudice to the subject.

Within this definition, agencies and researchers applying for HEW funds must provide assurances that this notion of informed consent is adhered to in project proposals.

The second critical aspect of the HEW guidelines involves the concept of peer review. The government suggests that such committees be composed of at least five individuals with varying backgrounds to assure the review of activities conducted by the applicant organization. Not only should the committee

possess the professional expertise to provide counsel, but must also be in a position to provide judgment concerning legal, ethical, and social implications of the research proposal.

Earlier references in this paper to the utilization of prisoners and the mentally disabled suggested that this practice is often rationalized as being necessary for the common good of mankind. To prevent abuses and provide safeguards for prisoners and the institutionalized mentally disabled, HEW has established policy guidelines. With respect to the institutionalized, mentally disabled, HEW guidelines state they may not be included in research projects unless the proposed activity

is related to the etiology, pathogenesis, prevention, diagnosis, or treatment of mental disability or the management, training, or rehabilitation of the mentally disabled and seeks information which cannot be obtained from subjects who are not institutionalized mentally disabled (Federal Register, 39, 165, Friday, August 23, 1974, p. 30655).

Informed consent from the individual, or in cases where the individual is not competent, from his legally authorized representative must be obtained in accordance to government guidelines on informed consent.

Finally, in any proposals involving the use of prisoners, safeguards are established which prevent undue inducement, provide for the determination that research would be appropriate for nonprisoners, protect the prisonersubjects from undue pressure to continue in the project, and assure withdrawal without prejudice or punitive action.

Regardless of the quality of HEW guidelines, they have served to encourage institutions and researchers seeking federal funding to implement procedures to safeguard human subjects.

Implications for Research with Human Subjects in Education

To this date, the problems of safeguarding human subjects faced by the medical and psychological disciplines have been obviated by educational researchers. Traditionally, educational research has been viewed as low risk,

and therefore immune to concerns for the safeguarding of the subject. Even if one were to agree in principle that educational research is low risk, thus having little possibility of violating the social-emotional-intellectual integrity of the subject; we must be ethically and morally committed to the premise that regardless of the presumed low risk nature of educational research, the possibility that the integrity of a subject could be violated necessitates our considering the issue of preserving the rights of human subjects.

It seems evident that recent developments may serve to restrict the use of data on school students, thus greatly diminishing educational research in this area. In an article which appeared in Educational Researcher, February 1975, the author pointed out that the provisions of the General Education Provisions Act (commonly referred to as the Buckley Amendment) will probably have a profound effect on educational research. Davis (1975) suggested that students may withdraw from longitudinal studies once the purposes of the studies are disclosed. Local school districts, fearful of the impact of the Buckley Amendment, may become far less cooperative than they were in the past. Finally, to provide adequate safeguards for the privacy of the subjects, and to administer the study to adhere to federal guidelines will greatly increase the cost of research involving student, data.

It is apparent that educational researchers as part of the larger body of behavioral scientists, must take immediate steps to confront the issues involving the use of human subjects. There must be a concerted effort to establish free-flowing lines of communication not only within the educational research community, but throughout the public sector as well. As educational consumers, the society at large is entitled to information involving the design, conduct, potential benefits, and results of research endeavors. As parents of research subjects, or subjects themselves, they are entitled to the fullest protection of human dignity and welfare that the educational research community can provide.

Unless educational reserachers themselves take the initiative, we could find ourselves subject to narrowly defined ethical guidelines which place unqualified restrictions upon the conduct of research in education. Such restrictions could have deliterfous effects upon the education of future generations.

It is altogether clear that it is incumbent upon the educational reserach community to develop a code of ethics which protects the rights and dignity of the human subject while fostering the conduct of meaningful, productive research.



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